'MOOC' as a platform for social learning, research and social change in dementia

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Abstract

Dementia is a complex syndrome affecting brain functioning. During 2015 we ran a MOOC on Dementia aiming to use the platform as a vehicle for social change encouraging discussion and dialogue around the subject. Over 3000 learners participated in discussion forums encouraing social learning and interaction. This paper presents our experience of running the course and how we have used the MOOCto address two health care research questions.

Keywords

Dementia, Social learning, Social change, Impact, Research

Experience track

1   Background

Dementia is a complex syndrome which affects brain function. It relates to an irreversible loss of cognitive ability and memory with a significant decline in behaviour, social and emotional capacity (Kitwood 1997; De Bellis et al. 2008; World Health Organisation (WHO) 2012). Although often seen as such, Dementia is not a normal part of ageing and many people who have a diagnosis are able to continue a positive quality of life, live in the community and maintain their independence. Dementia is a progressive disease and can reduce a person's ability to undertake normal daily activities which can lead to dependence on family memebrs and carers. Dementia is becoming a significant public health issue, and there are associted demands on health and social care systems (De Bellis et al. 2008).

The World Health Organisations estimates that number of new cases of dementia each year worldwide is nearly 8 million, meaning as many as one new case every four seconds. The number of people with dementia is expected to nearly double every 20 years, to 65.7 million in 2030 and 115.4 million in 2050.

During 2015, we ran a Massive Open Online Course (MOOC) on Dementia entitled 'Bridging the Dementia Divide' which attracted 3,070 learners from a wide variety of professions, backgrounds and locations. We chose to run our course on dementia due to its importance in culture, society and its effects on the future of civilisation with the hope that the course might become a vehicle for social change and stimulate dialogue around the subject. This paper presents our approach to the MOOC, considers its impact and also presents two research projects that have arisen as a result of the MOOC.

2   Our MOOC

'Bridging the Dementia Divide' ran for six weeks in duration with associated learning activities. As a MOOC, the course involved some aspects from an accredited University-level course delivered through online distance learning. The course sought to provide a higher education experience to participants who might not be able to access this mode of learning. We also hoped that the course would provide a platform for peer engagement and social learning; participants in the course varied significantly from nurses to occupational therapists to members of the public.

Activities were designed to encourage a reflective, person centred-approach to dementia and ask participants to consider their own experiences of dementia. For example, one of the initial questions asked participants to share their own experience of dementia and many of the responses were detailed and personal, demonstrating real insight into dementia.

There was a strong focus on quality, and each week had identified content and learning outcomes. The table below outlines the first three weeks of the course and their associated activities.

Unit	Unit title, theme and indicative content	Unit learning outcomes (visible to learners)	Indicative activities may include
1	**Introduction to dementia** What is dementia and why is it important? Indicative content: • Types of dementia • History of dementia care • How the brain changes with ageing • How the brain changes with ageing	1. Learners will demonstrate a critical understanding of dementia, challenging its myths and stereotypes.	1. In the discussion boards, introduce yourself. 2. Outline your reasons for undertaking this course; do you have personal experience of dementia? 3. Write a short reflection on the challenges facing society in meeting the health and social needs of people with dementia. Remember to be

			reflective in your thoughts; use an example to illustrate how this directly applies to your situation. Formative Quiz
2	**Communication and Compassion** Why is effective communication important and how can you show compassion? Indicative content: • Compassion as a concept • Models and principles of compassion • Compassion in dementia care • Communication techniques	1. Learners will evaluate the main theoretical perspectives applicable to the study of 'compassion' in care. 2. Learners will demonstrate a critical awareness of enhanced communication skills to enable them to better communicate with people with dementia.	1. Share a website related to communication or compassion, which could be a government organisation or charity, from your own context. 2. Create a mindmap [support and definition will be given] of techniques you could use to help carers of people with dementia to communicate their needs. Share your mindmap on the discussion board. You could create your mindmap digitally or draw it on a piece of paper and then photograph the image with your smart phone or scan it. Formative Quiz
3	**Independence, control and quality of life** How can you help the person living with dementia to maintain independence, control and a good quality of life	1. Learners will discuss techniques to defend independence, control and quality of life within the context of dementia, evaluating relevant ethical and	1. What ethics and values apply to you? Are ethical principles universal? Share your thoughts on the discussion board. 2. Review Jacques'

	Indicative content: • Self-determination and the maintenance of independence • Ethical and legal challenges to enabling and respecting self-determination • Ethical theories • Consent and capacity	legal frameworks.	comments on paternalism and consider whether paternalism in some form or another is inevitable in dementia care. Discuss this in the discussion board. 3. Reflect on the views expressed regarding euthanasia, particularly as applied to those with dementia. Share your thoughts as a group about the implications for those in need of ongoing care for dementia. [Optional activity] Formative Quiz

3 Impact

Throughout and after the course we have obtained valued student feedback through the MOOC discussion boards. We hope to include both feedback and student-generated content in future iterations of the course. Some general comments from students include:

> *"The content and the activities. Well written authoritative textual content and an impressive array of found and newly developed videos often featuring excellent stories of practice from carers and practitioners on the dementia frontline."*

> *"The course was well planned, easy to navigate with high quality content."*

> *"The ease of use, the availability, the content. It was excellent!"*

> *Students found the content to be scientific and academic, but at the same time accessible:*

> *"The content of the course covers the whole topic of dementia from scientific until end of life. I love it."*

> *"The Course was really scientific with each tutor replying and engaging with us and our questions having studied them first. The most amazing Course I have ever attended and I have to say I will miss such an engagement with specialists like the ones from the University of Derby."*

In terms of wider impact, this remains to be observed, but there is some early evidence that the course has had real impact externally:

> *"I've already signed up to volunteer with a few dementia patients overseas. Having gained the pre-requisite knowledge, I'll be able to identify more easily signs of dementia in a client since I'm working at the community level, assist families and educate them about the condition as well as advocate for a national dementia policy in my country."*

> *"I am now a member of a dementia focus group and attending workshops and seminars. Also able to add this topic to my education courses"*

> *"I may volunteer as a dementia friend"*

Students were awarded badges for completion of units and 67.75% of participants received at least one badge. We were able to demonstrate a retention rate of 35.48% which is considerably higher than rates on other platforms which have generally been reported between 5-8% (Ho et al 2014). Videos in the MOOC, which consisted of ten interviews with subject specialist in fields related to dementia, were viewed nearly 12,000 times on You Tube.

4   Using MOOCs for Research

The main purpose of this submission is to outline our experiences of using the MOOC for research purposes and demonstrating the potential for extracting

qualitative research data on important health and social care research questions. We see MOOCs as acting as a platform for social change, and as such, proposed two exploratory qualitative research questions.

Data was extracted from two MOOC discussion board activities, which comprised of 1695 MOOC discussion board posts. The data was analysed using the Framework Analysis approach (Richie and Lewis, 2003), which involved categorizing the data into themes and organizing the themes into charts to explore the findings across all of the participants' MOOC discussion board posts.

Experiences of Dementia

The first research question aimed to explore participants' individual experiences of dementia. It focused on exploring the variation in clinical experiences of treating and managing dementia, as well as considering wider health care and resourcing influences. It also considered personal accounts of dementia, looking at carer experiences and the role of social support.

Integrated Care

The second research question aimed to explore MOOC participants' definitions of Integrated Care for Dementia, as well as their perceptions of its strengths and weaknesses. The data suggested that Integrated Care for dementia should be patient-centred and holistic, involving a multidisciplinary team of health and social care practitioners, as well as the patient, the family and the wider community. The establishment of Integrated Care for dementia was overall viewed positively, although it was recognized that it presents challenges such as role conflict, lack of funding and often poor coordination of care. Enablers for Integrated Care included the introduction of shared communication and IT systems to allow information continuity and assigning an appropriately qualified care coordinator for each patient to ensure the patient's care plan is implemented effectively.

Conclusions

MOOCs provide opportunities for social change through their potential for internet mediated research. Our experiences of using MOOC discussion board posts as qualitative research demonstrate their effectiveness in providing research data that can improve our understanding of real world health and social care issues.

References

De Bellis, A.M. and Williams, J. (2008). The Cornell Scale for Depression in Dementia in the context of the Australian Aged Care Funding Instrument: A literature review. *Contemporary Nurse,* 30(1) pp. 20-31.

Ho, A. D., Reich, J., Nesterko, S., Seaton, D. T., Mullaney, T., Waldo, J., & Chuang, I. (2014). HarvardX and MITx: The first year of open online courses. *HarvardX and MITx Working Paper No. 1.*

Kitwood, T.M. (1997) *Dementia Reconsidered: the Person Comes First*. Buckingham: Open University Press; Brooker D (2004) What is person-centred care in dementia? *Reviews in Clinical Gerontology* 13: 215–22

Ritchie J, Lewis J (2003) *Qualitative research practice: a guide for social science students and researchers*. London: Sage.

https://www.canvas.net/browse/uderby/courses/bridging-the-dementia-divide *Acccessed 3.12.15*

World Health Organization and Alzheimer's Disease International. Dementia: A Public Health Priority. Geneva: World Health Organization; 2012. pp. 92 93.http://www.who.int/mental_health/publications/dementia_report_2012/en/